

Helping Parents Raise Healthy, Happy, Productive Children¹

by Nemours Health and Prevention Services and The California Endowment

Overview

Parents today are trying to raise healthy kids in a world much different from the one in which they grew up. It's hard for moms and dads to stay on top of what their children do, see and eat. And there is little support for parents – not just to keep their kids healthy, but also to prepare them to go out into the world and succeed.

While America invests in education, welfare and health care for children, the functions are largely a patchwork of disconnected programs that do not address the myriad of health issues facing today's children.

Just looking at medical care, children are living with a legacy of programs designed at a time when infectious diseases posed a widespread health threat. Put into place a generation ago, these 40-year old programs and policies, while extremely important, are not fully capable of addressing today's real and growing risks – obesity, mental illness, chronic disease. It is time for a change.

We need a child health system in America designed for the way kids today live and grow. We should adopt a comprehensive, coordinated approach that addresses the health and well-being of the whole child, including the child's physical environment and social service needs. And this approach should consider these needs over the long-term, not just in early childhood.

What is at stake is not just the health of children today, but the health of America tomorrow. The modern epidemics we face have life-long consequences and present significant costs to the economy. And many are preventable. Our failure to ensure the health of our children may jeopardize our children's ability to function

Nemours Health and Prevention Services and The California Endowment have supported a group of national and state policy experts in the development of this proposal. The members of this group include: Debbie Chang, Helen DuPlessis, Christine Ferguson, Neal Halfon, Laura Hogan, Sara Rosenbaum, Lisa Simpson, Deborah Klein Walker and Barry Zuckerman. The policies proposed in this document represent those adopted in this group process and do not necessarily reflect the views of their organizations.

effectively as adults and our ability as a nation to remain strong and competitive in our global society. Children who grow into adults with suboptimal productivity will have long-term economic and social consequences.

We are raising a generation of children who, for the first time in our history, are likely to be less healthy than their parents and live shorter lives.² It is a tragedy in the making, and one that is all the more disheartening because these new threats are largely preventable. They are often the result of a child's physical and social environment. They are rooted in the way our children live and learn and play. They can – and should – be fixed.

This proposal outlines a child health system that better coordinates health care, education, child care and wellness in a way that makes sense for families today. It suggests how to build on what works, and to transform what does not. It outlines central policy elements that would: (1) establish meaningful health coverage with benefits that support healthy growth and development; (2) make systemic changes to improve the quality, effectiveness and efficiency of care for children; and (3) make children a top priority at all levels of government. All three of these policy elements are critical and should be done simultaneously.

Like other major advances in American history, this change will not happen overnight or in a vacuum. It requires dedicated action among many to focus on what works.

It is time, and it is possible. Let us begin.

What is the Problem this Proposal Will Address? Children are not simply small adults. Unlike their parents, the main job for kids is to learn and grow, but America does not have a system in place that supports healthy growth and development. Simply downsizing adult-sized health and social programs ignores the problems children face today.

Here are a few of the challenges that this proposal will address:

- Nearly 9 million American children are uninsured.³ For millions more, insurance is sporadic, unstable, and often inadequate because benefits fail to focus on prevention, promoting good health and healthy development.
- America spends 95 percent of our health dollars on medical care and just five percent on promoting health and prevention.⁴ This imbalance is true throughout the system, but hits children the hardest because the most fundamental purpose of health care for children is to promote healthy development.
- The incidence and types of chronic disease in children have both increased and changed dramatically over the past four decades.⁵ One in every five children has a mental health problem.⁶ The number

of overweight children over the last three decades has tripled for preschoolers, tripled for adolescents, and quadrupled for children 6-11 years old.⁷

- The quality of services and access to these services reflect significant disparities in geographic, racial, ethnic and socioeconomic status.
- The administration and delivery of child health programs at all levels – federal, state, and local – is often ineffective, uncoordinated and incomplete. Programs vary widely across states with little accountability for quality at any level.
- In politics, the interests of children have often been overshadowed by groups who wield far more influence.⁸ This translates to less medical research, quality measurement and emphasis on the sharing of best practices in child health services than in other areas of health care.

What is the Proposed Solution?

The 2004 Institute of Medicine report, *Children's Health the Nation's Wealth*, offers a broadened definition of health. It focuses on outcomes and provides a solid scientific basis for action. It says children's health should be defined based on whether they can a) realize their potential; b) satisfy their needs; and c) develop the capacities to allow them to interact successfully with their biological, physical and social environment.

Although genes do dictate some health conditions, a scientific consensus is emerging that views health not as something set at birth, but rather as a state that develops over time as a child interacts with the physical and social environment.

America needs a children's health system that incorporates the IOM's broader definition of child health and development, addresses present-day health threats, focuses on prevention and promoting health and development and keeps pace with the latest scientific advances.

Based on the comprehensive model and the lessons learned from creating a system that serves the needs of seniors, it's essential that we make a similar pledge to our children. For seniors we have established:

- Universal health coverage;
- A defined benefit package with reasonable limits on premiums and cost sharing;
- A basic level of income security; and
- An organized system of community-based health, nutrition and social support services.⁹

It is time to provide the same supports to help parents raise their children.

This proposal outlines an outcomes-based child health system that emphasizes and coordinates the services essential to promoting the health and development of children. In short, the proposed solution would assure:

- Every child in America has meaningful health coverage that supports healthy growth and development;
- The children’s health system has an updated infrastructure with a 24/7 focus on policies and programs that are responsive to parents and providers (e.g., child care workers, schools) who care for their children; and
- The health and well-being of children are among the nation’s top priorities.

What is the Focus of This Proposal? It’s All About Desired Outcomes.

The United States must make adequate investments in health care and wellness, education and other services that families need, but we have learned that simply spending more does not mean getting more.

- Recent findings from a 2007 UNICEF report indicate that the U.S. now ranks second to last among the 21 industrialized nations surveyed in child well-being.¹⁰
- Similarly, in 2003, the U.S. infant mortality rate was 28th among industrialized nations.¹¹

It is time to better use the resources we have to get a greater return on investment – better outcomes and healthier children. The focus of this proposal centers on providing an outcomes-based system that provides the supports and services they need to assure children are healthy, safe, enjoy and achieve, contribute to society and achieve economic well-being. The final page of this paper provides more detail on these outcomes for each stage of development to ensure that progress toward these outcomes can be measured.

Proposal For Change: A Three-Point Plan To Update America’s Child Health System

In order to transform America’s child health system to truly meet children’s needs, the following three steps (of equal importance) must take place:

- First, we must provide meaningful health coverage for all children that supports health and development;

- Second, we must piece together fractured programs where accountability lies in many different places and create a seamless set of programs and services that will support a coordinated, holistic approach to children's health and well-being; and
- Finally, we must make meeting the developmental needs and promoting the well-being of children a national priority.

The following three-point plan outlines some of the steps that should be taken to achieve these goals. No single action alone is enough – we need a comprehensive, transformation of the child health system to reach these goals.

POINT ONE: Provide Meaningful Health Coverage for All Children that Supports Child Health and Development

The first step must be to ensure that every child in America has meaningful health coverage with benefits that support healthy growth and development. Children's coverage should focus on promoting health and helping ensure children grow up healthy. This means coverage for more than just treatment of diseases and illnesses, but also services and care to promote healthy development and well-being.

There are a variety of approaches for achieving universal health coverage for children, using different mechanisms and funding sources. This proposal does not take a position, however, on which would be the most effective. Regardless of the approach used to provide universal coverage, national standards should be established to ensure that the coverage for every child, whether public or private:

- Guarantees uninterrupted care and affordable enrollment through a highly accessible system;
- Provides appropriate reimbursement for services that reflects a developmental standard of child health and wellness;
- Ensures that supplemental health and development services are available for those with or at risk for special health care needs, for example, chronically ill children;

Additional federal funds are essential to help pay for necessary integration and coordination activities and to help ensure seamless coverage for all children. In addition, new funding needs to be provided to encourage innovative state practices and encourage local level and family involvement in policy development and planning.

A new child health system requires that the responsibility for financing meaningful health coverage for children be shared – the public and private sectors have major roles and families must also assume some responsibility for securing coverage for their children. Steps also must be taken to provide information and support to parents to ensure that their children receive required immunizations, get regular check-ups and obtain the services needed to assure the best health

possible.

POINT TWO: Establish Mechanisms to Create Systemic Changes in the Way Children’s Health and Developmental Services Are Provided.

There are a variety of different ways to build the needed momentum to bring about the fundamental system changes needed to support a transformed children’s health system. It is important to note that children’s services historically have been provided at all three levels of government. As a result, this proposal outlines specific changes at the federal, state and local levels. In addition, the last section recommends an enhanced role for parents and families in the policy-making process. Some of the approaches to move in this direction include the following:

Establish a National Child Health Investment Advisory Committee.

One important step to help redesign our child health delivery system would be through the creation of an independent, national advisory body¹² to serve as the central hub for creating a measurement and outcomes matrix for all child health programs and then evaluate programs on an ongoing basis. Congress has already begun to address this need by including a new child health quality initiative in the proposed 2007 SCHIP reauthorization legislation that would, for the first time, provide clear authority and resources necessary to establish such measures and providing in the same legislation a mandate for the Institute on Medicine to study and report to Congress on the measurement of child health quality, including the provision of preventive care, and make recommendations to improve information provided on child health and health care quality. These child health quality provisions could be expanded to include an independent advisory committee as described above to measure programs against specific indicators of child health and well-being (See Table 1 for details).

Such an advisory committee also could be directed to make recommendations on how to best achieve these outcomes (Table 1) and periodically report to the nation on the state of child health in America and progress toward meeting goals. Its recommendations should extend to the public and private sectors. Although such recommendations would not have any enforcement powers or regulatory authority, they would provide guidance in these areas and help stimulate the changes needed.

Ideally, the new advisory committee would begin with setting national goals and progress milestones and then:

- Translate identified child health outcomes (see Table 1) into outcome measures that would be regularly monitored and updated as needed;
- Make recommendations for a comprehensive health and development benefit package that would include developmentally appropriate health promotion and other support services;

- Develop an outcomes-driven child health and development agenda, including recommendations for programs and financing;
- Make recommendations for ensuring coordination and integration of child health and development programs across and within federal departments. Initially, the efforts to coordinate and integrate might apply to seven key programs: Medicaid, SCHIP, the Title V Maternal and Child Health Services Block Grant, Head Start, foster care, child care and IDEA programs. Other child health and development programs, including those in the Agriculture and Education Departments, would be phased in; and
- Assess the impact of these steps and recommend ways to address ongoing needs.

The new advisory committee might also be empowered to obtain from an independent research group, such as the Institute of Medicine, evidence-based reports over a five-year period to inform and make recommendations to policy-makers and other leaders about effective system changes that will optimize the health of children. Such reports also would keep child health issues at the forefront of the national agenda. The Department of Health and Human Services (DHHS) would be the lead department accountable for overseeing implementation of the new advisory committee's recommendations.

Establish systems to assure accountability and coordination of services at all levels.

Accountability for achieving the desired health outcomes for children must be shared among federal, state and local governments and families. Stronger links and better coordination across children's programs would help ensure that the nation remains focused on achieving goals and tracking progress toward improving the health and development of children.

These accountability requirements – based on coordination, integration, management and planning – are described below.

- Comprehensive, shared outcome and performance measures for tracking progress across programs and services at the national, state and local levels;
- Consistent definition of “comprehensive and developmentally-appropriate health services necessary to achieve age appropriate outcomes for children and youth”;
- Common terms and definitions of fundamental concepts, such as what constitutes a covered service or permissible expenditure;
- Common, transparent eligibility standards across child health and development programs;

- Common reporting standards, definitions and shared information systems that are consistent with current privacy and security standards;
- Coordinated quality improvement system with ongoing and rapid feedback to all system stakeholders, including service professionals, payers, program administrators, and families;
- Cross-cutting evaluation plan for monitoring system impact over time;
- Secure, privacy-compliant electronic information systems capable of critical program exchange on services offered, quality monitoring and performance measurement, the creation of integrated individual health records, and the production of anonymous, aggregated data essential to measuring progress;
- Collection and timely reporting of population-based information on child health and development; and
- Processes for ongoing feedback and involvement from all stakeholders, including youth, parents and family members.

The federal government can play an important role in establishing a variety of mechanisms, including requirements for federal funding programs, to implement these accountability and coordination standards. They must be embraced, however, at all three levels of government in order to achieve success.

Realign federal programs to support a transformed system.

Conflicting lines of authority and restrictive funding rules create barriers to providing streamlined child health and development services. To address these issues, Federal laws should be modified and sufficient funds authorized to carry out: 1) the establishment and recommendations of the national advisory committee described above; 2) the needed coordination/integration of programs serving children; and 3) a new state innovation grant program to encourage states and localities to develop and implement new integrated models.¹³

One approach to resolving some of the conflicting lines of authority and bureaucratic barriers would be establishing within DHHS the position of “Deputy Secretary for Children” with authority to oversee all programs relating to children. This high-level position would coordinate the many disparate programs relating to children within DHHS and through legislation and executive action could be given the authority to work with federal agencies outside of DHHS such as the Departments of Agriculture and Education to enhance coordination and integration of children’s programs. Although these kinds of changes may challenge current jurisdictional lines, they are clearly needed to make the system truly serve children’s needs.

Ideally, the new Deputy Secretary would be empowered to ensure coordination and integration of federal children's programs using the budget process and authority as leverage. The Deputy Secretary would be given the responsibility of working to ensure that parents can access appropriate child health and development services, including medical, prevention and health promotion services for their children. And, using recommendations from the new advisory committee, the Deputy Secretary would develop and implement evaluation mechanisms to track outcomes and recommend periodic changes in the benefit structure to assure appropriate services are available to meet the needs of children as they grow and develop over time.

Establishing a regular reporting by the Deputy Secretary for Children to the White House on the status of children's programs would also enhance the visibility of these issues. Under such a system, the Deputy Secretary for Children annually would:

- Develop a unified policy and program agenda with estimated national spending goals for children; and
- Present, in cooperation with the national Advisory Committee, specific findings of integration and coordination across children's programs and progress toward goals.

Trust Fund for Children.

In order to make the progress needed, clearly significant new sources of funds must be provided. One option for securing new funding that should be considered is the creation of a Trust Fund for Children¹⁴ with a dedicated source of funding. The Deputy Secretary for Children at HHS would manage the Trust Fund. The trust fund would provide funding to: 1) ensure coordination and integration of children's programs at the federal, state and local levels; and 2) provide incentive grants to encourage innovation at the state level.

In order to provide adequate new resources, the dedicated source of funding should be designed to provide \$2 billion annually for this new trust fund. A portion of this funding could be available to children's programs as they were restructuring to better integrate with other programs at the state and local levels. The remaining funds could be distributed to states that were implementing innovative child health initiatives. A new, dedicated source of funding is needed to provide resources for this Trust Fund so that it is not subject to funding level variations during the federal appropriations process and is not financed at the expense of other social programs.

State and local level changes.

States could be required, as a condition of receiving federal health funding, to establish an entity responsible and accountable for all state policies and services related to children and youth as a means of ensuring transformation at the state

and local levels. In order to achieve truly integrated systems, the focus would need to expand beyond medical care, and include the broad range of determinants that affect child health. Each governor would be expected to assure that his/her state has a coordinated and integrated approach to caring for all children through age 21 by designating a state accountability organization. Financial support for the development of coordinated, integrated plans, and oversight of the plans could be provided through the new Trust Fund for Children. States could apply for “coordination and integration” funds through the Deputy Secretary for Children’s office.

The state-level entities would be expected to develop programs consistent with the coordination and integration of programs at the federal level. They would be responsible and accountable for planning, monitoring, establishing policies and administering resources and for demonstrating how their programs meet the needs of their communities.

As noted earlier, the Deputy Secretary for Children could make special grants available to states to encourage coordinated and innovative approaches to improving child health and well-being. For example, they could be used to help ensure that services were seamless from the families’ point of view. If a family applied for one type of benefit, the state would automatically check to see if they were eligible for any other type of state benefits. States also could be provided incentive funds from the Trust Fund for Children to establish partnerships with non-traditional entities like employers, community-based organizations, local funders and parents, as well as to coordinate efforts to improve child health across multiple sectors such as public health, child care, schools and civic/community organizations. The goal of these grants would be to experiment with new models to address the multiple determinants of child health and development.

Local government entities also could be encouraged to ensure coordinated and integrated approaches to improve the health and development of children and youth. A local entity could be designated to have local responsibility for planning, monitoring and carrying out the functions delegated by the state accountability organization. Local community stakeholders would participate in state and national planning and implementation efforts. The local entities would ensure that family representatives play an integral role in setting family accountability measures and milestones.

States would determine what constitutes the local geographic areas that cover all children and youth. In addition, each local area would establish one or more “child and youth resource centers” as a community vehicle for delivering and coordinating services in the community.

Role of parents and families in a transformed system.

Obviously, parents and families are responsible for the individual decisions about the care and services provided to their own children, but families also must be involved in all aspects of policy making, program design and implementation as well as setting and monitoring milestones for accountability. As changes in the current system are being proposed and debated, mechanisms must be created at all levels to ensure that the views and perspectives of parents and families play a central role in policy decisions and that they are provided the supports they need in carrying out their responsibilities.

POINT THREE: Make Child Development and Well-Being A National Priority

A key element in achieving these goals is raising the status of children in our national priorities. Some of the measures contained in this proposal, such as creating a high level position within the federal government charged with optimizing the coordination and updating of children's services within and across agencies or requiring states to establish similar structures, are important not only as system changes, but also as vehicles to generate greater attention to children's unique needs. Similarly, the establishment of a high level advisory committee to focus on improving child health systems and establish goals and standards to help ensure high level services can help elevate these issues.

But systems changes alone cannot produce the outcomes needed. Real change – transformational change – that will move child health to a new level will require political leadership, committed to making children a national priority. It will require providers, parents, advocates, elected and appointed officials at all levels, influential private sector groups, employers, workers, and people from a wide range of political perspectives to join together to make the changes in our child health system that are sorely needed.

Conclusion

At the end of the day, this proposal is about helping parents raise healthy, happy and productive children. This requires a better-performing system that focuses on the best possible health and development outcomes to ensure a future generation of healthy, happy, productive adults. This whole effort is tailor-made for American ingenuity since it requires looking at existing models, research and resources and applying them to today's needs. It is well past time to begin making the changes needed to create a better system for all children.

Table 1: Age-appropriate outcomes for children and youth ¹⁵					
Outcome	Birth - 3	4 - 5	6 - 11	12 - 18	19 - 21
Being Healthy	Free from preventable physical disease Optimal nutrition Optimal growth & development Optimal mental and emotional health and development Optimal oral health				
	Healthy births	Learning healthy behaviors	Healthy lifestyle Free from substance use/abuse		
Staying Safe	Safe from neglect, maltreatment, and exploitation or abuse of any kind Free from accidents or injury Safe from dangers in neighborhoods Free from bullying and discrimination Free from existing and emerging threats in the environment				
Enjoy and Achieve	Thriving in enriched environments Nurturing from parents				
	Optimal opportunities for play Engaging in developmentally-appropriate activities Ready for school		Attending and succeeding in school Participating in and enjoying extracurricular activities Optimal personal and social development		
Make a Positive Contribution	Engage with family and peers Develop positive developmentally appropriate relationships with peers				
			Develop self-confidence and exhibit capacity to address life challenges		
Achieve Economic Well-being	Free from poverty				
			Exposed to a variety of careers Develop skills in managing resources		
				Plan for further education, training, or employment after school	Engage in further education, training, or employment

¹ For purposes of this document, the word “children” refers to individuals from birth to 21.

² Olshansky, S, Jay, et al. “A Potential Decline in Life Expectancy in the U.S. in the 21st Century.” *New England Journal of Medicine*, Volume 352:1138–1145, March 17, 2005, Number 11.

³ DeNavas-Walt, Carmen, Bernadette Proctor and Jessica Smith. U.S. Census Bureau, Current Population Reports, P60–233. *Income, Poverty and Health Insurance Coverage in the U.S., 2006*. U.S. Government Printing Office, Washington, DC 2007.

⁴ McGinnis, Michael, Williams-Russo, Pamela and Knickman, James. “The Case for More Active Policy Attention to Health Promotion.” *Health Affairs*, Volume 21, Number 2, March/April 2002.

⁵ Perrin, JM, Bloom SR, Gortmaker SL. “Increase of Childhood Chronic Conditions in the United States.” *JAMA*. 2007; 297:2755–2759.

⁶ Kataoka, SH, Zhang, L, Wells, Kenneth B. “Unmet Need for Mental Health Care Among U.S. Children: Variation by Ethnicity and Insurance Status.” *Am J Psychiatry*. 2002; 159:1548–1555.

⁷ Ogden CL, Carroll MD, Curtin LR, McDowell MA, Tabak CJ, Flegal KM. “Prevalence of overweight and obesity in the United States, 1999–2004.” *JAMA*. 2006; 295(13):1549–1555.

⁸ Iglehart, John. From the Editor. *Health Affairs*. Volume 26, Number 2, March/April 2007.

⁹ Grason, Holly and Guyer, Bernard. “Rethinking the Organization of Children’s Programs: Lessons from the Elderly.” *The Millbank Quarterly*, Vol 73, No 4, 1995.

¹⁰ UNICEF, Report Card 7. “Child Poverty in Perspective: An overview of child well-being in rich countries.” United Nation’s Children’s Fund 2007.

¹¹ U.S. Department of Health and Human Services, Maternal and Child Health Bureau. “Child Health USA, 2006.” Rockville, MD: USDHHS, 2006.

¹² Currently, an independent advisory committee, MEDPAC, exists for providing guidance on Medicare issues for seniors.

¹³ The 2007 SCHIP reauthorization legislation, approved by Congress but vetoed by President George Bush, also contained a provision authorizing a new innovations demonstration grant program, allowing the secretary of DHHS to award up to 10 grants to states and child health providers “to conduct demonstration projects to evaluate promising ideas for improving the quality of children’s health care.”

¹⁴ The Trust Fund for Children would be created within the Treasury, with a dedicated revenue source, to assure the availability and stability of federal funds. The federal government has created separate trust funds for highways, airports, the disabled, the elderly, and the jobless. Likewise, there is a “children’s trust” in every state funded through mechanisms such as fees on birth certificates, marriage licenses, and special license plates. The 1991 National Commission on Children discussed the establishment of such a national children’s trust fund in its final report, “Beyond Rhetoric: A New American Agenda for Children and Families.” More recently, Congress has been moving forward on legislation to establish an affordable housing trust fund, using fees from various housing related transactions as a source of dedicated funding.

¹⁵ This table is based on work produced in a British report “Every Child Matters: Change for Children.”